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ORIGINAL ARTICLE

Health Care Experiences of Patients with Nonbinary Gender Identities

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Abstract

Purpose: The primary purpose of this study was to characterize the health care experiences of diverse patients with nonbinary gender identities across a range of geographic locations. A secondary aim was to use the qualitative findings to inform recommendations for clinics and providers to create gender-affirming health care environments for nonbinary patients.

Methods: We conducted 3 focus group discussions with 7–9 participants, for a total of 24 unique participants. To be eligible, participants were required to be 18 years of age or older, live in the United States, speak English, have the ability to access Zoom in a private room, have a nonbinary gender identity, and be able to attend one of three scheduled focus groups.

Results: Participants reported frequent negative health care experiences, including misgendering, invalidation, and pathologization, even within clinics that signaled alliance with transgender communities. Participants described strategies they use to cope with negative experiences, including health care avoidance, identity concealment, and seeking out providers that are matched in terms of gender minority status and/or race.

Conclusion: Recommendations for the provision of gender-affirming health care for nonbinary patients include nonbinary-inclusive intake forms and electronic health records, having providers be proactive in eliciting preferred names and pronouns, and requiring education for providers and staff at all levels on the provision of nonbinary-inclusive gender-affirming health care.

Keywords: gender affirmation; gender identity; health care experiences; minority stress; nonbinary

Correction added on October 23, 2021, after first online publication of August 17, 2021: The word *soliciting* has been modified to *eliciting* to more appropriately convey its meaning.

Introduction

Nonbinary people (i.e., people with nonbinary gender identities) are those whose gender identity is beyond the binary of male and female. Nonbinary genders include diverse identities such as genderqueer, gender nonconforming, agender, Two Spirit (specific to indigenous Americans), genderfluid, feminine of center, third gender, and others. Nonbinary identities are distinct from binary transgender (or "trans") identities, although some trans men and women may also identify as nonbinary. Gender minorities, including binary trans and nonbinary people, experience social marginalization and challenges accessing employment, housing, and legal protections due to gender-related stigma and discrimination.[1] Marginalization persists in health care, as gender-diverse identities continue to be pathologized and health care systems continue to erase and underserve transgender and nonbinary patients.[2]

Minority stress theory, originally developed with a focus on lesbian, gay, and bisexual people and adapted to include gender minorities, describes unique and chronic stressors due to structural stigma and discrimination associated with a sexual and/or gender minority identity.[3–5] Due to minority stress, gender minorities

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experience intensified health and mental health care needs that are exacerbated by marginalization in health care, which further drives disparities.[1,6,7] Gender minorities who are also black, indigenous, or people of color (BIPOC) experience even higher rates of health disparities due to the intersection of multiple marginalizing social forces, such as racism and transphobia, also referred to as intersectional stigma.[8] Binary trans BIPOC report feelings of being overlooked and anticipating stigma in health care settings,[9] as well as negative health care experiences due to provider responses to patients' racial and/or gender identity and assumptions about transgender people of color.[10] To date, health services research has not adequately characterized and documented the intersectional experiences of invalidation and other microaggressions that nonbinary BIPOC may encounter in medical settings.

Health care that affirms patients' gender identities improves mental health outcomes, health care utilization, social functioning, and quality of life.[11,12] Gender-affirming care is a patient-centered approach to providing evidence-based care to gender-diverse patients, in which health care providers are equipped with tools and knowledge to meet their unique health care needs.[13] When providing gender-affirming care, health care providers support and validate their patients' gender identities, document and use correct names and pronouns, and provide accurate information about and access to transition-related care, such as hormones and/or surgery (if desired by the patient).[13,14] While research has explored the impact of gender-affirming care on the health of transgender people from a primarily binary perspective, there is a lack of focused research on how health care providers can provide gender-affirming care for nonbinary patients specifically.[15]

The primary purpose of this study was to characterize the health care experiences of diverse nonbinary patients across a range of geographic locations and identify strategies they use to cope with negative experiences. The secondary aim was to use the qualitative findings to inform recommendations for clinics and providers to create gender-affirming health care experiences for patients with nonbinary gender identities.

Methods

Settings

We conducted focus group discussions (FGDs) in July 2020 through Zoom web conferencing with participants from 24 different U.S. zip codes and 6 states nationally.

Participants

We recruited participants through online advertisements on Facebook and Instagram, and word of mouth. From the pool of eligible participants, we purposefully sampled ($n = 24$) to achieve diversity in terms of age, race, zip code, and other relevant attributes, including having a chronic illness or disability.

We conducted 3 FGDs with 7–9 participants (total $N = 24$). To be eligible, participants were required to be 18 years of age or older, live in the United States, speak English, have the ability to access Zoom in a private room, and be able to attend one of three scheduled focus groups. Nonbinary identity was assessed by asking potential participants if they identify as nonbinary, as well as the open-ended question "what is your gender identity?." Participant responses to the open-ended

Table 1. Participant Demographics

Variable	*n* (%)
Age, years	
18–24	11 (46)
25–30	8 (33)
30–43	5 (21)
Sex assigned at birth	
Female	22 (92)
Male	2 (8)
Gender identity	
Nonbinary	24 (100)
Genderqueer	10 (42)
Transgender	2 (8)
Agender	5 (21)
Trans masculine/male	3 (13)
Transsexual	1 (4)
Demi-boy/neutrois gender	1 (4)
Gender nonconforming	1 (4)
Female	1 (4)
Race	
Asian	8 (33)
Black	4 (17)
Pacific Islander	2 (8)
Latinx	2 (8)
White	11 (46)
Middle Eastern	1 (4)
Mutiracial	5 (21)
Geographic location	
Urban	17 (71)
Suburban	6 (25)
Rural	1 (4)
Income	
I cannot get by on the money I have	3 (13)
I can barely get by on the money I have	7 (29)
I have enough money to live comfortably	14 (58)
Disability status	
Yes	12 (50)
No	8 (33)
Undisclosed	4 (17)
Insurance status	
Medicare/Medicaid	8 (33)
Private insurance	15 (63)

question included nonbinary, genderqueer, transgender, gender nonconforming, transgender male, transmasculine, agender, demi-boy, and neutrois gender. Two participants were assigned male at birth and 22 participants were assigned female at birth. FGDs were held with participants from rural (1), suburban (6), and urban (17) settings across 24 different zip codes (Table 1).

Data collection

The FGD facilitators received training on FGD facilitation and data analysis from experienced qualitative researchers. The research team, which included nonbinary-identified and/or BIPOC individuals, designed the FGD guide to explore experiences in health care settings, experiences of provider attitudes, strategies used to cope with negative experiences, and recommendations to improve health care experiences. FGD facilitation was tailored to build iteratively on emergent themes. Each FGD lasted ~90 min and had two facilitators that both identified as nonbinary. All participants provided verbal informed consent before participation. Participants were reimbursed with $40 Amazon gift certificates upon completion of each FGD. The study was determined to be IRB Exempt by the University of California, San Francisco, Institutional Review Board.

Data analysis

Data analysis was guided by a Framework Approach.[16] FGDs were recorded and transcribed verbatim. We used Dedoose to store, organize, and code data. During data immersion, team members read transcripts and noted follow-up probes for later FGDs. We then developed a preliminary codebook using a combination of deductive and inductive codes derived from findings. We revised the codebook as needed between FGDs to improve code definitions in the event of inconsistencies emerging between coders. We coded all data, analyzed code reports, and tabled data around key emerging themes. Throughout the analysis, we drafted memos that explored the relationships between themes and examined patterns by race and disability status.

Results

Misgendering

A primary theme described by nonbinary participants was inaccurate documentation of their gender identity in health care records, both in written communications and in their electronic health record. Participants described how this results in frequent misgendering (referring to a person using gendered language that does not align with their affirmed gender), leading to feelings of discomfort and erasure by health care systems.

> There were so many different pronouns in use in my medical records. There were all of them, all the options, and sometimes it was from my personal physician and sometimes it was just from the X-ray tech or people who didn't know me. And they never asked. So they kind of guessed.—Darwin, age 32, White, Focus Group 3

Assumptions by providers often led to misgendering and misnaming (using an incorrect name, such as a legal name, which a person no longer uses). Several participants described never being asked their gender identity by health care providers, despite the fact that eliciting preferred name and pronouns is a known critical component of gender-affirming care. One participant described not being asked their gender identity at any point during their multiple psychiatric hospitalizations, leading to them being placed in a female unit and being misgendered by providers throughout their hospitalizations.

Several BIPOC participants described feeling both misgendered and racialized by health care providers. One participant described providers performing in a racializing way by being overly familiar and using an impersonation of how some feel Black women speak to each other.

> If the provider is white/white skinned, a lot of providers have tried to [use] gendered language that I think is some kind of performance of how they think that I would interact with them. And so they'll be like, for example "Oh, hey, girl" and just talking to me like that. It's just weird, because we're not friends.—Sair, age 20, Black, Focus Group 3

Many participants described clinics utilizing "alliance signaling," or patient-facing messaging to signal gender inclusion in the clinic, such as advertising inclusive practices and soliciting patients' preferred names. Several participants described alliance signaling as beneficial when they had gender-affirming experiences at the clinic. A few participants described experiences of clinics initially using alliance signaling but then providing care that was not gender affirming, which significantly diminished trust as the microaggressions felt like a betrayal of the purportedly safe environment. For many participants, alliance signaling is frequently distrusted, given past negative experiences had in purportedly inclusive environments.

> I think something that's been really uncomfortable for me is when I'm in a clinic that says it's mindful of these things. And I'll be upfront about what pronouns I use and then get misgendered throughout the entire session. It's like I came in with this expectation and it was pretty much immediately ignored.—Rasa, age 18, Black/North African, Focus Group 2

Invalidation

When participants disclosed their nonbinary identity, they reported feeling frequently invalidated by their providers. This invalidation was intensified for some participants who had health care priorities directly related to their nonbinary identity. One patient described disclosing how their gender identity influenced their decision to accept a hysterectomy as treatment for fibroids, and how their provider reacted by invalidating their gender identity and health care priorities.

> [In discussing treatment for my fibroids] to my gynecologist, I mentioned keeping my ovaries but not my uterus. I explained I was nonbinary, and he just kind of scoffed and it was just very, very demeaning, and very uncomfortable to deal with.—Honey, age 20, Black, Focus Group 1

Scoffing, shrugging, or dismissing patients nonverbally sends the message that their nonbinary identity and related health care priorities are invalid. Participants also described feeling frequently frustrated that when they corrected providers around names or honorifics, they were often ignored. Many participants described enduring gendered honorifics like "ma'am," "miss," and "sir" from health care providers that persisted despite correction and suggested alternative forms of address.

Pathologization

Some participants described how documentation of their gender in health records was tied to psychiatric diagnoses from the Diagnostic and Statistical Manual (DSM) of the American Psychiatric Association. Several participants felt pathologized by these diagnoses and voiced frustration that their providers had documented mental health diagnoses like Gender Identity Disorder (DSM-IV) or Gender Dysphoria (DSM-5) in their charts after patients disclosed their nonbinary gender identity, despite the fact that the patients were not presenting with distress (a required symptom for diagnosis of gender dysphoria).

> There's no way for you to put a preferred name or even pronouns or gender. So when I came out to my PCP, she put in my record that I had Gender Identity Disorder, as a way to mark me as trans. It was very disconcerting.—Skyler, age 24, Chinese, Focus Group 1

Facilitators and barriers to coping

Participants outlined strategies they used to cope with persistent negative experiences in health care. One frequently cited strategy was the avoidance of health care altogether. Others described engaging with health care but choosing not to disclose their nonbinary identity to avoid experiences of invalidation or discrimination. Additional coping strategies included dissociation when receiving care and finding community support from other trans and nonbinary patients. Several participants noted that self-advocacy, or advocating for their identity and health care needs, sometimes led to feeling more authentically perceived by and safe around health care providers. Despite this, many participants felt uncomfortable self-advocating due to fears of judgment and/or discrimination.

For Black and other participants of color, racism was described as a major barrier to feeling safe enough to self-advocate. One participant described feeling unsafe to self-advocate due to intersectional stigmas related to gender identity, race, disability status, and socioeconomic status.

> As a disabled black person, one of the main reasons why I can't correct providers, why I don't feel comfortable doing so is because I don't want to be seen as angry or violent, or non-compliant. And also because the care that I'm getting is being paid for by somebody else [Medicare]… I just have to take it because, I could be getting nothing.—Honey, age 20, Black, Focus Group 1

Finding providers with similar identities, such as gender identity and/or other important identities, such as race and disability status, helped participants feel safer in seeking health care. One participant described how meeting with a nonbinary provider made them feel safer in health care encounters.

> With my current therapist they're also trans and nonbinary and they've been great. I just feel a little bit more protected, a little bit.—Nico, age 30, Mexican, Focus Group 1

Several participants described seeking providers who were both nonbinary and non-white, and challenges associated with finding such a provider. These participants described feeling forced to choose which identities to prioritize in care.

Recommendations for the provision of gender-affirming health care for nonbinary patients

Participants offered suggestions to make health care encounters more inclusive (Table 2). Participants noted the importance of educating all providers and staff in health care settings on how to ask about and document nonbinary identities and use gender-inclusive language, including language that decouples gender from body parts. Participants suggested providers be proactive about asking patients about their gender identity and documenting patients' pronouns in medical records.

> What would build that sense of safety is the onus not being on me or not being on the patient, where I'm already shown that this is a trans and nonbinary friendly atmosphere and to be

Table 2. Recommendations for Gender-Affirming Practices with Nonbinary Patients

Health care level	Recommendation	Supporting quote
Provider-level	Elicit every patient's gender identity and pronouns	"What would build that sense of safety is the onus not being on me or not being on the patient, where I'm already shown that this is a trans and nonbinary friendly atmosphere and to be shown that the provider takes the first step and then me as a patient would feel comfortable taking the second step."—*Madlyn, age 43, White, Focus Group 3*
	Confirm the name and pronouns of every patient	"I have a primary care physician and he comes in the door and always says my name and then asks if I'm still going by that name. I've always felt that's a really positive experience. Even if I haven't seen him very recently, he just does a good job of checking back up and not making assumptions about where I am in my life."—*T, age 29, White, Focus Group 1*
	Use patient's correct name and pronouns and describe anatomy without gendered language	"Using the right pronouns, de-gendering like body parts—I do not need someone specialized in like Transgender Health to do that, and it would make my life a lot easier."—*Andre, age 18, Hong Kongese/Middle Eastern/White, Focus Group 1*
	Be open to correction	"I froze my eggs last summer and the reproductive endocrinologist was explaining something, and they said the word 'women', and I said 'people', and she was like, 'You're right, thank you.' And then she moved on. And that was really wonderful."—*Jin, age 20, Chinese, Focus Group 1*
	Advocate within existing system for documentation to be more inclusive	"Something that made me feel supported was that when I decided to exclusively use they/them pronouns, my psychiatrist immediately was like, 'I don't know how easy it will be but I can help with trying to change all your medical records within the system to reflect that change.'"—*Max, age 22, Japanese/Brazilian, Focus Group 2*
Health systems-level	Include curriculum on the needs of nonbinary patients in health professions education	"Medical education needs to include education about trans people and nonbinary people."—*Charlie, age 33, White/Multiracial, Focus Group 2*
	Be intentional about alliance signaling	"I think something that's been really uncomfortable for me is when I'm in a clinic that says it's mindful of these things. And I'll be upfront about what pronouns I use and then get misgendered throughout the entire session. It's like I came in with this expectation and it was pretty much immediately ignored."—*Rasa, age 18, Black/North African, Focus Group 2*
	Create intake forms and electronic systems with standardized and nonpathologizing documentation of gender identity	"Something that's really easy would be to have better intake forms and to have a patient portal where you can put your pronouns and gender identity without having to get diagnosed with Gender Identity Disorder or other psych conditions."—*Honey, age 20, Black, Focus Group 1*
	Diversify provider pool to include more nonbinary providers, especially BIPOC providers	"Having more trans—particularly trans practitioners of color—I think would also, make a huge difference because then there's like that mutual understanding of shared experiences that a cis[gender] practitioner might not necessarily have"—*Rasa, age 18, Black/North African, Focus Group 2*

BIPOC, black, indigenous, or people of color.

> shown that the provider takes the first step and then me as a patient would feel comfortable taking the second step.—Madlyn, age 43, White, Focus Group 3

Participants provided several system-level recommendations, including to improve electronic health records documentation and intake forms to include nonbinary patients and to broaden the workforce of health care providers to include practitioners who identify as nonbinary. Many participants envisioned a future with more nonbinary doctors, especially more BIPOC nonbinary providers, due to a perceived "mutual understanding of shared experiences that a cis[gender] practitioner might not necessarily have."—Rasa, age 18, Black/North African, Focus Group 2

Discussion

In this study, nonbinary adults from a range of rural, urban, and suburban regions in the United States shared their health care experiences, including factors that contribute to minority stress and coping strategies. These findings expand the literature documenting challenges faced by trans people when navigating health care by exploring diverse experiences of nonbinary patients in terms of race, class, age, geographic location, and disability status. Our findings corroborate one study that reported nonbinary people experience frequent microaggressions, or subtle forms of discrimination in health care, including misgendering and misnaming.[5]

Consistent with a study on nonbinary youth in health care, we found that a unique challenge for nonbinary patients in particular (compared with binary transgender identity options) is providers' inability to see beyond the gender binary of male and female.[17] Our study further identified that health care documentation is a barrier to receiving gender-affirming care,

even when inclusive of binary gender identity options, While some intake forms and electronic health records have been expanded to include "transgender man" and "transgender woman" as gender options, most do not include nonbinary options. Providing several options for patients to report gender identity—through electronic records health systems, intake forms, and online communications—could improve patient experiences and allows the clinic to accurately document demographic data.

Our research identified several sources of mistrust for nonbinary patients in health care settings, including frequent invalidation of gender identity by health care providers.[6] Microaggressions toward nonbinary patients are experienced even in clinics that actively signal alliance with trans communities through advertising inclusive practices or soliciting preferred names from patients. We found these overt signals of trans alliance are insufficient on their own to interrupt the minority stress experience among nonbinary patients and must be followed up with nonbinary-inclusive gender-affirming care, including correct name and pronoun use, to retain patient trust and engagement with care.

Participants expressed that it is a priority—and a challenge—to find providers who offer gender-affirming care. Our study uniquely identified priorities for nonbinary patients, including BIPOC patients, to work with providers with competency in seeking, documenting, and verbally reflecting patients' nonbinary gender, racial, and ethnic identities. Given the structural inequities and discrimination that create barriers for many gender minorities and BIPOC individuals aiming to become medical providers, nonbinary BIPOC study participants often felt they had to choose providers that either shared or understood their gender identity or were matched in terms of race and/or ethnicity, but that having a provider that was both was nearly impossible to find.[18,19]

Participants described multiple strategies to cope with negative health care experiences, including identity concealment, or the decision to not disclose nonbinary identity in health care settings to avoid stigma and discrimination from providers. We found that BIPOC nonbinary patients may be even more likely to conceal their nonbinary identity from providers due to anticipated intersectional stigma on the basis of race and gender identity.[20] Furthermore, many participants described foregoing health care altogether due to anticipated stigma and invalidation by health care providers, as has been described in existing literature examining health care experiences of transgender people of color.[10]

The provision of gender-affirming health care was identified by our participants as critical to building trust and feelings of safety within health care systems and in relationships with providers.[11] Based on these findings, we generated recommendations for health care clinics and providers to make health care environments safer and more gender affirming for nonbinary patients. Recommendations include mandatory training on gender-affirming care for all health professionals and having providers initiate conversations with patients about gender identity. System-level recommendations include nonbinary inclusive intake forms and electronic health records and having more providers, including more BIPOC providers, across specialties who identify as nonbinary.

While this study included diversity in race and ability status and participants from a range of geographic location, participants from urban and suburban settings were overrepresented compared with rural regions and included only two participants assigned male at birth. Focus groups took place on Zoom, which increased our study's reach across diverse geographic locations, but prevented participation for those without access to this technology. Furthermore, we were only able to accommodate participants who spoke English.

Conclusion

Health care providers and health systems must provide nonbinary-inclusive gender-affirming care to reduce persistent health disparities. Our findings directly inform quality improvement efforts that seek to improve health care experiences among nonbinary patients. Future research should identify strategies to build trust and improve engagement in health care among nonbinary patients, particularly for BIPOC patients and patients with disabilities who face additional health disparities and barriers to quality health care. Targeted interventions are urgently needed to address the health and health care disparities among nonbinary patients.

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Authors' Contributions

J.B. and J.S. conceived the study. J.B. and A.N. collected and analyzed data. S.Z.H. contributed to data analysis

and writeup. J.B. produced the first draft of the article. All authors contributed to editing and finalizing the article.

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The authors have no conflicts of interest to declare.

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Abbreviations Used

BIPOC = black, indigenous, or people of color
DSM = Diagnostic and Statistical Manual
FGDs = focus group discussions